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# The Data-Gathering Broker – A User-Based Approach to Viable EPR Systems

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## Abstract

*With the continued expansion of Electronic Patient Record systems ahead of comprehensive evidence, metrics, or future-proofing, European health informatics is embarking on a faith-driven adventure that also risks data swamping of end-users. An alternative approach is an information broker system, drawing from departmental data sources. A three-year study in health and social care has produced a first demonstrator which can search for specified information in heterogeneous distributed data stores, with source-specific permission can copy it, and then merge the search results in a real-time process.*

## Keywords:

Electronic patient records; Information broker; Departmental systems, Pervasive technology; Enterprise systems; Information swamping

## 1. Introduction

One of the biggest drives in health informatics in Europe is the development of Electronic Patient Records (EPRs). These have built upon a series of innovations in both primary and secondary care in many countries, not least the Netherlands, Finland and the United Kingdom, but have been encouraged forward by the seminal study of the US Institute of Medicine [1].

This unswerving drive forward seems obvious, and yet is unsupported. The obviousness comes from the powerful support to clinical diagnosis and healthcare delivery through the marshalling, analysis, searching, and representation of clinical data in a way which is totally impossible with paper-based records. Yet EPR systems are as much built on faith and instinct as balanced evidence. The Institute of Medicine Report [1] showed a high level vision, but was remarkably devoid of facts: there is no mention of record size, volume of transactions, or likely areas of further development. There are many instances of successful EPR developments, at practitioner level, institutional, and generic commercial level. Yet there are also cautionary tales of over-stretching [2], as well as a considerable literature on sub-optimal use. It is thus difficult to determine whether European health systems are embarking on a vision, a dream, or a nightmare.

## 2. Inexorable Growth of Vision

A further challenge is that as EPR systems develop, so there is a multi-dimensional inexorable growth extending the vision in many uncoordinated directions, principally:

**Vertical integration** – primary care and secondary care records are seen as of much greater benefit when they are linked into one single shared view of the patient.

**Horizontal integration** – records based on a single institution can lead to fragmentation of care, hence a move to regional records.

**Temporal integration** – previous medical history is often important in diagnosis, hence the interest in the concept of the electronic cradle-to-grave record.

Thus three dimensions of extension are leading towards vastly larger EPRs, yet it is claimed no system is yet complete [3]. However, even this is not the full story.

## 3. Expansion to Unsustainability?

These dimensions of integration are challenging in that they take record size, record storage, and transactions to previously unforeseen volumes. There are, though, further extensions, as current healthcare and diagnostic techniques themselves are growing inexorably, in very data-hungry ways, as is ‘pervasive’ technology potential. The following trends all cause further rapid expansion of EPR requirements:

**Digitisation of Investigations** – increasingly, x-rays, pathology results, ultrasound scans, and other diagnostic technologies are digitised in space-hungry formats.

**Volume of Investigations** – efficiencies from avoiding duplicate investigations are offset by the drive to undertake more investigations, particularly scans and traces.

**Population Longevity** – average life expectancy is increasing, and old age leads to increasing healthcare support and monitoring, increasing record size exponentially.

**Genetic Analysis** – genetic information increasingly is used as part of diagnosis and treatment, but detailed genetic code is large and therefore storage-hungry.

**Designer Drugs** – increasingly drugs will be tailored to the individual, and also “orphan” drugs will be utilised for patients with rare conditions. The prescribing part of records will grow rapidly to accommodate person-specific pharmaceuticals.

**Domestic Environment Monitoring** – as those with health conditions affecting their independent living are encouraged to live in their own homes, so “intelligent” housing monitoring systems will expand, and must be seen as part of the health record.

**Continuous in vivo Monitoring** – wearable monitoring devices and intelligent clothing are being developed both for diagnosis and to monitor daily living. The results must be part of health record, expanding far beyond current telemetry data.

**Remote Service Delivery** – increasingly telemedicine and other forms of remote healthcare delivery will be utilised, and must be included in the EPR.

The consequence of these cumulative drivers is rapid inflation of record size and the volume of transactions. Is this the uncontrolled evolution of a dinosaur which ultimately cannot be sustained? Experience from commerce is not encouraging, with large integrated enterprise systems proving vulnerability to instability and failure.

## 4. User Challenges

The physical growth of the EPR causes challenges for end users from the sheer complexity of the record, with increasing skill needed to navigate all the material – a typical incomplete

EPR system having 27 000 screen formats, 10 000 being used by ward nurses [4]. Data swamping is as much a potential risk as data shortage.

## **5. Is Doomsday upon Us?**

This analysis is salutary, in that it makes the current instinctive drive forward to the integrated EPR vision look like a rush to an unsustainable solution. It is time to ask whether alternatives are possible. The motive of getting the relevant information to the right clinician at the right time is entirely laudable, and with the recent rapid developments in storage and communication powers the integrated record has seemed the natural solution, but expectations are now moving beyond the original vision.

At the same time, new means of searching for, retrieving, and handling data mean that much smaller record stores can be utilised as a virtual large facility if harnessed appropriately. For instance, though every airline runs its own reservations system, the consumer can now use services that present an integrated picture of all the possible routes between any two destinations for a specified date and time, then look for seat availability and prices for any option [5]. This is done not through data warehousing, but by accessing all the autonomous systems in real time and presenting to the end user in a standard display. The autonomy, and the different data formats, of the individual systems are not compromised, but the user receives an integrated picture.

## **6. The Broker or Data Gatherer**

The new tool which achieves this vision is a broker - software which can register all potential data sources, find the relevant ones to meet a specific user query, and with approved permissions read the required data to create a real time picture. Of course, health is complex, with highly tuned requirements for confidentiality, and rich and varied sets of data items stored in many formats. However, a demonstrator broker has now been developed in the health and social care setting.

## **7. The IBHIS Project**

This project was the Integration Broker for Heterogeneous Information Systems (IBHIS) project of the Universities of Keele, Durham, and UMIST\* working as a consortium, funded by the UK Engineering and Physical Sciences Research Council (EPSRC) from 2002-2004. A web-based demonstrator linking data sets in real time now exists. Papers and presentations have been made to Medinfo 2004 [6] and UK Health Computing 2005 [7], to healthcare audiences, and international software and web service conferences [8,9].

The Information Broker solution rests on developing two key principles - that the end-user has situation-specific information requirements which need external data, and that local "departmental" record systems are generally robust. With paper records these two principles were in conflict, but the electronic information broker achieves the hitherto impossible. It acts as the user's agent, seeking defined information on demand about an identified patient, and presenting it in collated form without compromising the source systems' integrity. The work of the IBHIS team demonstrates this is possible in the health domain. If this were to be the architecture of the future, clinicians could have rich but relevant information at the point of decision-making, whilst the data could be held in

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\* From October 1<sup>st</sup> 2004, UMIST and the Victoria University of Manchester have merged to become The University of Manchester.

departmental and small systems, and new component record paradigms could be added without any overall change.

## 8. The Components of IBHIS

Because of the health domain demands the IBHIS broker has many components, listed below and shown in Figure 1:

- User authorisation (to access IBHIS)
- System authorisation (to gain access to a remote system, with its controls)
- Customised user screens (to meet different user needs).
- System and data inventories (to know who holds what, in what form).
- Ontology encyclopaedias (to record and translate data formats).
- Audit trails (to know who has used the system, with what results).

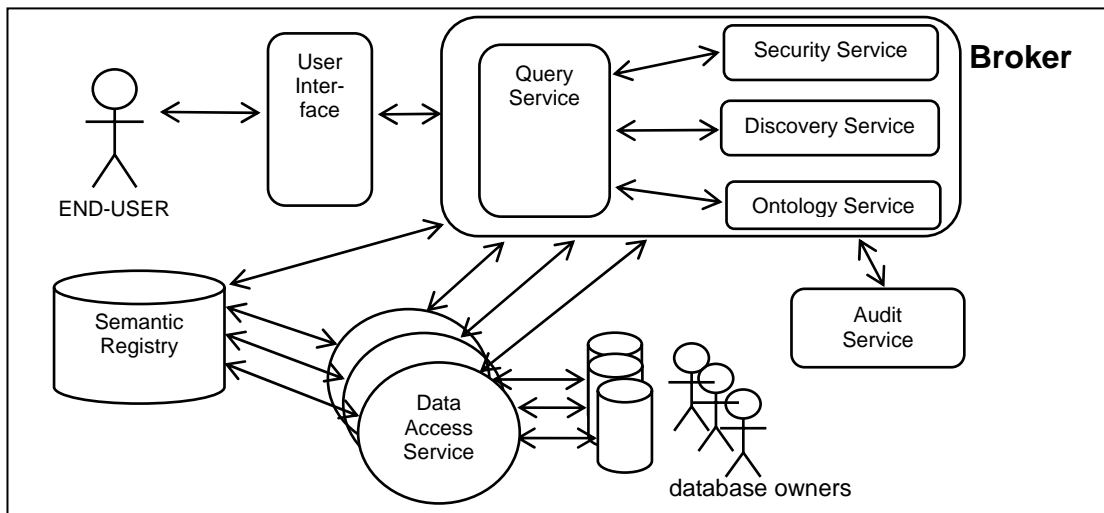


Figure 1: Conceptual Design of the IBHIS Enquiry Process [7]

## 9. The Vision of IBHIS in Action

Once the user has logged on, identified the patient by one of a number of identifiers, and stated the type of information required, the ability of the IBHIS system is to:

1. verify that the user's enquiry matched their permissions (permissions depend on identity, assigned roles, team membership, and the contexts of the access);
2. visit all the participating data repositories and identify all possible relevant matches for that identity;
3. visit (with permission) those systems to extract the data items requested;
4. using the ontology encyclopaedia, bring together the data items;
5. finally, check that the data aggregation would not create unauthorised disclosure of information by inference; and then
6. display the result, whilst the audit function would record not only the enquiry made, but the result as displayed

## 10. Purposeful Technical Components

The core components of the IBHIS broker are summarised in Figure 2:

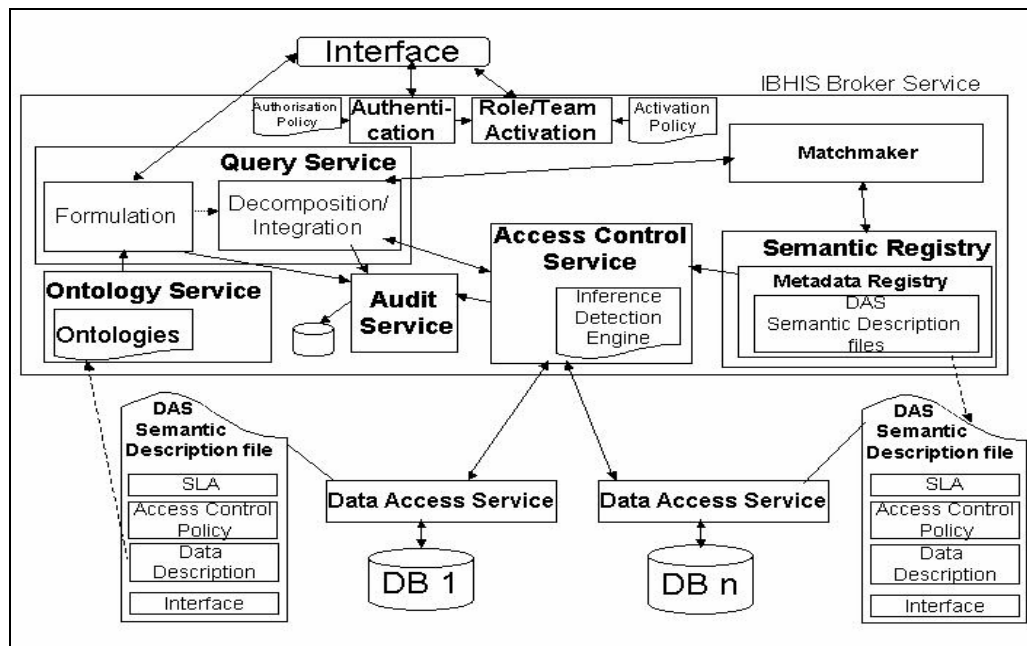


Figure 2: Conceptual Architecture of the IBHIS Broker [7]

The operational system comprises the following key components:

1. **Graphical User Interface (GUI)** – through a login screen authenticates the user, allows the user to navigate the domain ontology and guides him/her through query formulation, passes the query to the Query Service, and displays the results.
2. **Access Control Service (ACS)** - responsible for user authentication and authorisation, (special research having been done on service-based access control).
3. **Ontology Service (OS)** - consulted during the query decomposition and integration process.
4. **Query Service (QS)** - comprising two sub-modules:
  - *Query Decomposer* decomposes the Query into a set of local queries, in consultation with the matchmaker and the semantic registry which holds the semantic descriptions of the Export Schemas.
  - *Query Integrator* - receives and integrates the individual results from the DASs.
5. **Audit Service (AS)** - comprised of two sub-modules, which keep track of every action of IBHIS that needs to be recreated or audited in the future.
  - *User Audit* (per session): holds information such as: user log-in date, time, IP, logout, sequence of Queries, sequence of Results, etc.
  - *System Audit* (per Registration): holds information about Data Source (e.g. registration date and time, intervals of availability, etc) and User Setup (e.g. time stamped creation, deletion, profile update, user registration/deletion etc)
6. **Data Access Service (DAS)** - the operational core, constructed using Web services. For each enquiry the QS decomposes the enquiry into a set of sub-queries, uses the Registry Service (see below) to look for DASs that provide the required data outputs; then uses the DAS description to bind with the data services.

The system is set by loading the **Registry Service** with details of available data sources, and the **Matchmaker Service** with the roles, users and access rules. The **Ontology Service** holds relevant ontologies harmonising results.

## 11. Current Status – Emerging Results

The IBHIS project team has now completed three years' work, at the end of which a laptop-based demonstrator is available for use anywhere with a telephone line, running live on distributed autonomous dummy data systems. Interest is being shown in a number of health and care domains, including child protection, an acute hospital (several ideas for collating local distributed information), and a primary care team.

## 12. Conclusion

The health information broker appears to offer a viable future alternative to the meta-enterprise very large EPR system. It would have the advantages of enabling users to feel in charge of their information support and the data systems. It could support European citizen mobility. Moreover, as new functions such as genetic records, pervasive technology and personalised drugs come into use, recording of these can be in dedicated systems yet fully accessible to end-users as and when necessary.

## 13. Acknowledgements

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